

**Lyme Disease Advisory Committee Meeting
March 10, 2004, Sacramento, California**

The tenth meeting of the Lyme Disease Advisory Committee (LDAC) was held on March 10, 2004, in Sacramento, California.

Committee members in attendance

Victoria Deloney, Ph.N., Sacramento County Public Health
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Peggy Leonard, Lyme Disease Resource Center
Susie Merrill, Lyme Disease Support Network
James Miller, Ph.D., University of California, Los Angeles
Scott Morrow, M.D., M.P.H., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Committee members not in attendance

Lee Lull, Lyme Disease Support Network

Other attendees

Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services
Approximately 15 people representing the interested public and public agencies

I. Opening comments

The meeting was brought to order by the Chairman, Chris Parlier, at 10:15. Eight members were present.

Dr. Kjemtrup indicated that the California Department of Health Services (DHS) Office of Legal Services had prepared a document on the Bagley-Keene Open Meeting Act in response to questions from the Committee. The document had been emailed to the Committee and was in their packets. Mr. Parlier requested that such documents, including the agenda, be mailed out as a hard copy at least one week before the meeting, as well as in email format, so that the Committee would have ample time to go over the material.

II. Review and approval of minutes of the March 25, 2003, meeting

Ms. Peggy Leonard read a statement from Ms. Lee Lull expressing that the minutes did not adequately reflect Ms. Lull's concern regarding the agreement that educational material written by the California Department of Health Services (DHS) on tick-borne diseases should be reviewed by LDAC before distribution. Specifically, she felt that DHS physicians who had communicated with colleagues about Lyme disease (LD), using their DHS email addresses and equipment, were circumventing the LDAC. She requested that DHS physicians who communicate with the medical community about LD diagnosis and treatment

should consult first with the LDAC as agreed upon previously. No correction for the minutes was offered nor was the statement signed.

Discussion among committee members regarding the statement and how to address the issue for the minutes ensued.

Dr. Morrow moved to approve the minutes as written, Ms. Deloney seconded the motion.

One member of the public commented that if the minutes were not correct then they should be corrected.

The motion was voted on and passed with five aye votes, one no vote, and two abstentions.

The Committee discussed the process of approving meeting minutes. Members provided suggestions to improve timeliness for distribution and website posting of the minutes, while keeping within the guidelines of the Bagley-Keene Open Meeting Law.

Dr. Morrow motioned that within 30 days of an LDAC meeting, minutes will be distributed to the Committee (email and hardcopy) and that within 60 days of the meeting, there will be a teleconference to discuss and vote on the minutes. Ms. Leonard seconded the motion. There was no public comment. The motion passed unanimously with eight votes.

III. Review and approval of LDAC minutes of the May 1, 2003, teleconference

Dr. Miller motioned to approve the minutes as written. Dr. Lane seconded the motion. There was no public comment. The motion passed with seven ayes, zero no and one member abstained.

IV. DHS progress report (Dr. Anne Kjemtrup)

Dr. Kjemtrup gave a progress report on DHS-Vector-Borne Disease Section (VBDS) activities pertaining to tick-borne disease (TBD) education of the public, physicians, and other agencies.

Committee discussion on the report centered on results of the physician questionnaire on Lyme and other tick-borne diseases, published in the February 1, 2004, *Action Report*, published by the California Medical Board. Concern was expressed about the low response rate of physicians to the questionnaire. The low response rate is an indication that this Committee has much work to do towards physician education on TBD awareness and prevention. Dr. Morrow noted that DHS may have a Computer Assisted Telephone Information system

that may be helpful in contacting more physicians directly and specifically. Ms. Deloney suggested that information on LD could be published in *Nurse Week*, a publication sent to all California nurses and Ms. Leonard also suggested *Advance* as another nurse's publication that would be effective for disseminating information on LD to the medical community. Mr. Parlier suggested that publications for physician assistants would be another important venue to publish information on tick-borne diseases in California.

Dr. Kjemtrup mentioned that the VBDS website (<http://www.dhs.ca.gov/ps/dcdc/disb/disbindex.htm>) has posted material useful for physicians. She acknowledged the staff of VBDS and other participating agencies as important contributors to her progress report and to the data posted on the website. Dr. Kramer stated that one of VBDS' biologists, Ms. Lucia Hui, has made valuable contributions to the TBD program and that she would be retiring later this year. Dr. Morrow observed that within the state system, when someone retires, they are not replaced.

Dr. Lane motioned that the Committee write a letter to the Director of DHS to support VBDS and protect positions within the section. Dr. Miller seconded the motion.

Members of the public offered the following comments:

Ms. Hui's position needs to be replaced because there is an urgent need for scientists to address the public health emergency of LD.

The letter to the Director should be copied to the DHS Administration and to Senator Chesbro, the senator who sponsored the legislation (SB 1115) which created the LDAC.

The Committee agreed that the letter would be on LDAC letterhead and signed by Mr. Parlier. Ms. Leonard volunteered to draft the letter.

The motion was voted on and passed with eight aye votes, zero no votes; one member abstained.

V. Committee member reports:

A. Senate Health Committee Informational Hearing (Parlier)

Mr. Parlier reported on the Senate Health and Human Services' Committee Informational Hearing on LD, sponsored by Senator Debra Ortiz, on February 25, 2004. A video of the hearing is available at Calchannel.com.

The hearing took place on the same day Assembly Bill (AB) 1091 was first read in the Senate. AB 1091 allows DHS to change the reportable disease list in

consultation with the California Conference of Local Health Officers (CCLHO), without having to go through a lengthy regulatory process.

Mr. Parlier made a motion that the LDAC should write a letter to the Director stating that LDAC supports the passage of AB 1091 because it will facilitate DHS to make LD laboratory reportable, thereby improving surveillance for LD in California. Ms. Leonard seconded the motion.

Mr. Parlier made a second motion that the LDAC should write a letter thanking DHS for participation in the hearing, specifically mentioning Dr. Mark Starr's testimony on disease reporting. The letter would be copied to Senator Ortiz. Dr. Lane seconded the motion.

A member of the public offered copies of the text of AB 1091.

The first motion was voted on and passed by eight aye votes, zero no votes, and one abstention.

The second motion was voted on and was passed unanimously.

B. Human behaviors and Lyme disease risk (Robert Lane)

Dr. Lane reported on findings from a study performed by his laboratory and recently published in *The Journal of Medical Entomology* (<http://esa.edoc.com/server-java/Propub/esa/me-v41n2.contents>).

Dr. Lane summarized the research. It is currently known that leaf litter is an important risk factor for acquiring nymphs. In an experiment where different behaviors were evaluated in terms of risk of acquiring nymphs, it was discovered that the behaviors associated with acquiring ticks in order of highest to least risk were: 1) sitting on logs, 2) gathering wood, 3) sitting against trees, 4) walking, 5) stirring and sitting on leaf litter, and 6) just sitting on leaf litter.

In light of these findings, the Committee made the following suggestions:

- Include the new information about exposure to wood or logs as an important risk factor for acquiring nymphal ticks in DHS educational material on tick-avoidance techniques.
- Amend the recommendations that self-examination for ticks should be done each day for at least three days after being in tick-habitat since the nymphal ticks are often difficult to detect. The longer the tick is attached, the more likely a localized skin reaction will occur which can facilitate detecting the tick.
- Include a link to Dr. Lane's article in the spring press release.

C. International Lyme and Associated Diseases Society (ILADS) guidelines for the management of Lyme disease (Dr. Raphael Stricker)

Dr. Stricker reported that ILADS produced guidelines for physicians on the treatment of LD. He felt that this publication was the first comprehensive guideline for treating LD and would likely become the standard of care. Over 3,000 copies have been distributed in the past five months. Currently, the guidelines can be purchased from ILADS (<http://www.ilads.org>) but they will be available for free in six months.

VI. Physician-public education

Dr. Kjemtrup presented an example of wallet-sized cards that are being developed to provide information about common human biting ticks in California. The card will create awareness about ticks and provide useful information on tick removal. Some cards will be printed by DHS, but they will also be available via the DHS website for downloading and printing. Specific suggestions from the Committee regarding this card included:

- Create separate card for relapsing fever.
- Include a photo of an engorged tick on the card (replace the wood tick photo).
- Make the male *Ixodes pacificus* darker.
- Use a vertically oriented ruler next to the ticks to give size measure.
- Re-title the card; "Ticks of California" does not describe the card well.
- Add a reminder that other tick-borne diseases exist in California.
- Try using actual size photos rather than silhouettes.
- Replace "tick paralysis" with tularemia.

IV. Physician education

A. Prevention Poster: Dr. Kjemtrup presented a tick-bite prevention poster. The purpose of the poster is to make it available to physicians to post in their offices for patients to read. Suggestions from the Committee regarding the poster were:

- List or display more repellents and put "tm" next to each.
- Emphasize importance of prompt removal of ticks.
- Make poster available in two downloadable and printable sizes: 11x14 inches and 8.5 x11 inches.
- Make sure to convey the message that tick checks should be done two to three days after being exposed to ticks.
- Replace the phrase "Not all ticks are infected...." with "Remove all ticks promptly!"

- Replace “often” with “regularly” in the following phrase: “Check each other often while in tick habitat” and replace “while in tick habitat” with “where ticks are found, such as grass, forest, etc...”
- Add the DHS – VBDS contact phone number.

B. Physician education strategy: The Committee brainstormed on ideas to reach physicians about tick-borne disease awareness and prevention messages. Specific suggestions were to:

- Contact Deans of California Medical Schools to provide information on tick-borne diseases in California and emphasize the importance of including curriculum on tick-borne diseases.
- Direct materials towards nurses who often serve as a conduit of information for physicians.
- Put information in *Nurse Week* and determine if there are any nurse conventions in California that would be amenable to seminars.
- Include the Physician Poster in 8.5 X 11 inch format as a pull-out poster in the *Action Report*.

V. Public education

A. Health fair poster

Dr. Kjemtrup presented a poster entitled, “Tick-Borne Diseases and Tick Bite Prevention.” This large poster is intended for health fairs. Dr. Kjemtrup is often contacted by people who need illustrations about tick-borne diseases in California for health fairs. Several copies of this poster would be made available for check-out and the poster would also be available on the website. Specific suggestions from the Committee on the health fair poster included:

- Make the same changes as suggested for the physician office poster.
- Take out “adult” in “adult tick habitat.”
- Put in more photos of the EM rash: possibly all four that are in the brochure.
- Change the color of the sentence about allergic reactions to tick bites from green to yellow. Restate the phrase as, “Allergic skin rashes can occur 1-24 hours after a tick bite.”
- Rephrase the last sentence under “Expanding rash” to read, “The EM is rarely itchy or painful.”
- Create a poster oriented to children and suitable for posting in schools.
- Create posters in Spanish.

B. Tick-testing Q & A sheet

Physicians and the public often call DHS-VBDS with questions regarding testing of ticks for *B. burgdorferi*. Dr. Kjemtrup presented a question and answer (Q & A) sheet that addresses many of the common questions. This Q & A sheet would be posted preceding the “Testing results of ticks that bite humans” database that will

be eventually posted on the website. A detailed discussion of each question ensued. In addition to grammatical corrections, the following specific suggestions were offered:

- Point out that, in general, nymphal infection prevalence is greater than that of adult infection prevalence.
- Clarify the concept of a false positive test result.
- Include a link to the CCLHO website so that people can locate a phone number for their local health department.
- Also include a link to the Mosquito and Vector Control Association of California (MVCAC) so that the public can contact their local vector control agency. Some vector control agencies will identify or test ticks.

VI. Public comment

(Five members of the public spoke)

Terry Mitchel Charonnet: Ms. Charonnot is a Lyme patient. She was appreciative of the convenience of the new DHS location but requested that notices of meetings be posted sooner so more people could attend. She offered specific suggestions to DHS regarding the material presented at the meeting:

- The title of the tick wallet card should include the words Lyme disease, e.g., *“California ticks can transmit Lyme disease in California.”*
- A red dot should be placed next to the tick that transmits LD.
- The wallet-sized cards should be included in medical practitioner’s license renewal letters.
- The tick card could be made into a bookmark for school kids.
- LD prevention messages could be put on grocery bags.
- Dr. Lane’s new information on exposure to nymphal ticks on logs should be included in any media releases.
- Posters could be sent to small newspapers (ready-made art).
- Graphics of ticks drawn by children could be used on the posters for doctor’s offices as this would attract more attention.

She would like to see it mentioned that LD is a sexually transmitted disease.

Stephanie Propp – Ms. Propp is also an LD patient. She was dismayed at the low response from physicians to the questionnaire. She felt that waiting an additional one to two years before issuing another questionnaire is too long. She suggested that the LD brochure should be included in the *Action Report*.

Dr. Herb Dorken - Dr. Dorken is a legislative lobbyist for the California Lyme Disease Association (CALDA). He noted that CALDA is the new name for the Lyme Disease Resource Center. CALDA is a sponsor of AB 1091. He summarized some upcoming activities for CALDA. CALDA will be presenting at the next state meeting for nurse practitioners. Next year, CALDA hopes to have a continuing education symposium for nurses. CALDA is completing a survey form for Lyme patients that will be mailed out to Lyme patients this month. CALDA has

a list of physicians whom he described as Lyme literate physicians and this list currently has 60 physicians on it. CALDA plans on submitting legislation next year. Dr. Dorken mentioned that there is a short article by Dr. Stricker that recently appeared in *Expert Opinion in Investigational Drugs*.

Ken Waller: Mr. Waller stated that he has been a LD patient based on positive test results since 1998. His primary care doctor within his HMO was not experienced in LD diagnosis and treatment. He read from a letter from the Department of Managed Health Care to whom he submitted a letter of complaint. The letter stated: "A licensed California physician consultant reviewed the lab results you submitted and records. First, the consultant states there is no objective evidence of Lyme disease. This opinion takes into account the problems associated with false positives, which may mislead patients to believe that they have a problem, which they do not. Second, as to any claims about being a Lyme disease specialist, there is no special training or degree for this disease. Any board certified infectious disease specialist has the same knowledge and skills to diagnose and treat this condition. A good deal of misinformation exists on the Internet regarding conditions such as Lyme disease. Additionally, patient expressions of improvement or feeling better after antibiotic treatment is not evidence for efficacy. The belief that Lyme disease is the only explanation for your symptoms does not appear to be valid." Mr. Waller asked if there is any mechanism to communicate information on LD in California from DHS to the Department of Managed Health Care.

Dr. Stricker commented that he has seen many versions of this letter. Dr. Morrow made the motion that the section of the letter read in public comments should be included in the minutes from this meeting. Ms. Merrill seconded the motion.

There was discussion among the committee as to whether it was appropriate to include this information from another agency in LDAC minutes and as to whether it was appropriate to raise a motion during public comment period¹.

The motion was voted on and passed with eight aye votes, zero no votes, and one abstention.

Philip Hammond: Mr. Hammond is a Lyme patient in San Francisco. He expressed appreciation of the information contained in the VBDS annual report, particularly the tick-testing data. However, he felt that more historical information needed to be included in the report and that the report did not indicate which counties are the highest risk for LD.

¹ DHS Office of Legal Services has determined that the addition of action items that are not posted on the agenda is not permitted unless it complies with Government Code 11125 (<http://caag.state.ca.us/publications/bagleykeene.pdf>). To correct this motion and voting error, the motion will be put on the teleconference agenda for a revote. Pertinent Government Code is found at the link listed above and includes sections 11125 a, b, and 11125.3 (1, 2) and 11125.5.